

## **What did we learn about citizen involvement in the health policy process: lessons from Brazil**

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# **What did we learn about citizen involvement in the health policy process: lessons from Brazil<sup>1</sup>**

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In this paper I argue that citizen involvement helped to promote a more equitable distribution of public health services in Brazil. This achievement involved a balance of contributions from social actors and health system managers in forging policy innovations and institutional arrangements that linked bottom up innovation with national policy leveraging and decentralized implementation. The paper briefly describes this cycle and its relation with the implementation of a national network of forums for citizen involvement in health policy, inquiring in more detail the conditions that favor the association between these forums and the policy making process. Our results do not corroborate the idea that deliberative arenas should be insulated from political passions; rather, they suggest that participation of mobilized social actors contributes to the effectiveness of these forums. This contribution happens both due to the knowledge that these actors bring about problems in the area and to their insertion in networks that connect forums to a wide set of social organizations and political, governmental, and health institutions, which in turn facilitate the dissemination and negotiation of the proposals and demands formulated by the forums. Despite these achievements the results also call attention to a slight increase in inequality in the distribution of basic services between the poorest regions.

In the beginning of the 1980s it became clear in Brazil, as well as in a number of other countries, that greater resources for public healthcare were allocated to wealthier regions and citizens. Over the next few years, the difficulties in overcoming this distributive pattern gained momentum in the public policy literature and by the end of this decade there were different pathways being described as possible avenues to overcoming distributive inequalities in the health sector. Of the several possibilities being discussed at this time, two gained the particular attention of governments, scholars and donors: citizen involvement and decentralization. The idea was that both could contribute by promoting innovation, accountability for the needs of the poorest citizens, and social control.

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In Brazil this agenda gained political relevance after the enactment of the “Citizen Constitution” in 1988. In addition to declaring health to be a universal right of citizens, the Constitution replaced the old public health system with the SUS, or Unified Health System. At the time of its creation, the SUS reflected the aspiration for a system that integrated the local, the state and the national levels as well as preventive and curative medicine. Recent data show that the SUS has, in its 20 years, been working for the poor, as efforts have successfully been made to achieve a more balanced distribution of resources between the worse and better off regions. Also, in addition to the reduction of inter and intra regional inequalities, there has also been a decline in health inequalities between the population as a whole and some of Brazil’s most vulnerable groups (MS 2010; IPEA 2009; Siops 2008; Souza 2003).<sup>2</sup> Nevertheless, there was also a small increase in the inequality in the distribution of basic services within the poorest areas and groups, which I will refer to as horizontal inequalities<sup>3</sup> (Shankland 2010, Coelho et al 2010a).

In this paper I begin by calling attention to the debate on citizen involvement and policy change. I then present the results of a research program that, during the last ten years, has made systematic inquiries into the relationships between citizen involvement and changes in the distributive profile of public health services in the city of São Paulo. The paper concludes by discussing features of these processes that can be improved in order to strengthen the processes’ accountability to the most vulnerable and least mobilized groups.

In the next section, I review different theoretical and analytical approaches to the relationship between citizen involvement and policy change. In section three, the cycle of innovation that emerged during the 1990s within the SUS is described. Section four presents the methodology developed to allow for a more systematic analysis of performance and the capacity to impact policy of the formal participatory arenas. This methodology was tested in the city of São Paulo. In section five, the results of this work are presented, pointing to: 1) A reduction in the disparity between the supply and

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<sup>2</sup> See Annex 1, which presents data on Brazil showing a reduction in inter-regional inequalities and data for the Municipality of São Paulo showing a reduction in intra-regional inequalities.

<sup>3</sup> I use the term horizontal inequalities to refer to inequalities that grow between groups that depart from similar socio-economic features. They result from a process where sub-groups leave behind other sub-groups with whom they had shared membership of a broader, formerly excluded group (“peasants,” “indigenous people,” “the urban poor,” etc.).

consumption of public health services across the areas with the best and worst indices of income, education and health; 2) A slight increase in inequality in the distribution of basic services between the poorest areas; 3) A positive association between citizen involvement, mobilization and these distributive results. Finally, in section six, a summary of findings is presented which moreover includes suggestions concerning features of participation that may contribute to tackling horizontal inequalities.

## *2. Linking citizens to the policy decision making process: a brief overview of the debate*

In parallel with a public policy debate that argues for decentralization and participation as pathways to promoting government accountability to citizens' needs and preferences (UNDP 2002), there is an academic debate focused on improving the quality of democracy. Theorists of deliberative democracy, deepen democracy, and participatory governance have been discussing how procedural, institutional, and social features can improve the quality of citizens' political involvement.

Authors associated with deliberative democracy theory believe that the core idea of democratic deliberations is that decisions are made with more and better information and these decisions come to be accepted as legitimate and justified by participants. They call attention to the process of decision-making and offer nuanced criteria for assessing the quality of these processes (Habermas 1997; Dryzek 2001; Mansbridge 2003). Those associated with deepen democracy argue that citizenship should mean far more than just the enjoyment of legal rights and the election of representatives, highlighting citizens' potential to collectively mobilize in order to be directly involved in deliberation and decision-making on political and policy issues (Gaventa and Cornwall 2001; Heller 2001; Avritzer 2002). Finally, those associated with participatory governance are particularly interested in how to coordinate these new and more participatory political arenas with the congressional and executive governmental bodies. They inquire about the institutional framework in which these bodies interact with a view to developing and implementing policies that are more accountable to citizens' needs (Fung and Wright 2003; Melo and Baiochhi 2006).

Departing from these perspectives, in the 1990s and 2000s, there were an important number of studies on Southern and Northern empirical experiments that were concerned with the impacts of decentralization and public involvement.

In summarizing the findings of research on decentralization, Robinson (2007) points to the absence of cross-national and cross-sectoral studies on the impacts of decentralization on service delivery outcomes. In a partial review based on available case studies, he concluded that improved equity outcomes have generally not been achieved and that the quality of public service provided has not improved as a result of restoring power and resources to local governments. Regarding the Brazilian experience, Medici (2001), Ugá, Piola, Porto and Vianna (2003), and Marques and Arretche (2004) drew attention to the fact that improvements in access to services in all Brazilian regions reflected increased resources invested rather than a more equitable distributive profile. According to these authors, this profile remained skewed in favor of more prosperous regions. Souza (2003) and Melamed and Costa (2003), on the other hand, stated that decentralization measures had increased equality in the distribution of resources and access to services across Brazil's regions, states and municipalities.

Authors working with 'new democratic arenas' in the South, such as Participatory Planning in Kerala, the Participatory Budget in Porto Alegre, and the Health Councils in São Paulo, for example, suggested that under certain conditions concerning design, the mobilization of civil society and involvement by public managers, redistributive gains and an increase in the political participation of traditionally marginalized groups in the political process do occur (Abers 2001; Wampler and Avritzer 2004; Coelho and Nobre 2004; Lavallo et al. 2005). Researchers focused on deliberative experiments that took place in the North in turn have demonstrated that deliberative processes contribute towards changing the positions and opinions of participants, attenuating the process of polarization concerning controversial policy issues (Abelson and Gauvin 2006).

More recent studies ended up pointing out that, despite this good news, important questions with respect to the democratic potential of these new democratic arenas remain unanswered (Melo and Baiocchi 2006; Cornwall and Coelho 2007; Dagnino and Tatagiba 2007; Bebbington, Abramovay and Chiriboga 2008; Warren and

Urbainatti 2008). For example, in Brazil, India or South Africa, given the rules that organize participation in deliberative processes, how can we check whether traditionally marginalized groups with no political party connections or relationship with public managers, were included in the process or accessed its distributive benefits? Furthermore, how can we tell if there is greater accountability in the way that the policies are being provided? Are the public policies that are being generated from information provided by civil society representatives innovative?

In short, these empirical studies confirm the relevance of the theoretical approaches described earlier and, at the same time, call attention to the fact that these perspectives have been studied separately. They also highlight that there is currently no well-established knowledge about the quality of the processes (inclusion, legitimacy, involvement, and transparency), their capacity to impact the policy process, or the quality of the outcomes that are being associated with participation (innovation, distribution).

To deal with these questions, we developed a methodology that helps to assess how far public involvement and social mobilization have come in promoting inclusion, deliberation, and innovation in health policymaking. We also inquired about how these features may be related to changes in the distribution of public health services.

To investigate the extent to which public involvement promotes inclusion, deliberation and innovation, we followed the approach of a group of researchers (House and Howe 2000; Rowe and Frewer 2004; Abelson and Gauvin 2006, Ansell and Gash, 2007) who have highlighted the need to construct models that make it possible to analyze and compare arenas for citizen engagement. At the core, for these authors, is the possibility of identifying procedures and incentives that favor the expression of demands by those who have fewer resources. These authors also recognize the importance of investigating the location of these arenas within governance structures.

To deal with the impact of different types and trajectories of mobilization in the forums' performance, we followed another group of authors (whose ideas are published in Cornwall and Coelho eds. 2007) who suggest the importance of social mobilization processes in guaranteeing conditions so that actors that have fewer resources are able to participate. In parallel, authors who deal with the broad notion of social capital maintain

that desirable levels of participation and deliberation, along with positive outcomes, can only be achieved in social environments that have at least some record of civic engagement and political mobilization (Putnam 1993; Verba et al., 1995; Costa 1997).

To identify changes in the distributive profile of public health services, we developed a geographically-based methodology that uses data from the Health Ministry and the Demographic Census to monitor distribution of basic appointments and hospital admissions (Coelho and Silva).

In this paper I present a preliminary set of findings that resulted from the application of this model, with the expectation that they will contribute to a better understanding of the conditions and mechanism that link participation to the policy decision making process. In the next section, before entering into this analysis, I briefly present the cycle of innovation that guaranteed the institutionalization of a robust framework for citizen involvement in Brazil. In doing so, I hope to make the nature of the mobilization processes to which I am referring clearer, as well as the type of health governance structure currently in effect today in Brazil.

### *3. Bringing the citizenry back in: describing a cycle of innovation*

The cycle of innovation that made it possible for the SUS, the Brazilian Public Health System, to successfully tackle entrenched inequalities over the last twenty years is clearly related to the development of a new governance structure and can be summarized as follows:

- (i) In the late 1980s and in the 1990s, there was a bottom-up process with decentralized (civil society and municipal or state level) programs being created and successfully tested before becoming National Programs. At this stage, civil society associations and social movements played an important role in disseminating the notion of health as a citizen's right and engaged in a number of local initiatives such as, for example, creating local health councils and HIV-AIDS initiatives. One of the most successful Brazilian programs dealt with HIV-AIDS, wherein organized civil society pressed for a more comprehensive

approach than the one recommended at the time by the World Bank and the government;

- (ii) Contracts began to be signed between the Health Ministry and the Municipalities for the full management of health activities. The contracts define responsibilities and transparent financing rules for the implementation of the national health policy. In this division of responsibilities the Ministry provides funding and sets policy but does not directly deliver services. At this stage, the “Brazilian Health Movement” played a crucial role, advocating for the effective institutionalization of the health conferences, a national health council, and also health councils in all twenty-six states and in nearly all of the 5,561 municipalities. These forums play a decisive role in regularly engaging civil society in a way that allows for challenges to be posed to the Health Authorities on policy rather than civil society merely having a participative role in implementation. As a result, there is increased citizen involvement, transparency and accountability;
- (iii) At the local level, the proportion of municipalities taking decentralized responsibility for aggressive programs of primary care increased from 23.4 percent to 88.7 percent. As an example, in 1995, 1 million users were registered with the Family Health Program (PSF); today 97 million out of 140 million Brazilian SUS users are registered.

As we can see, public involvement played a decisive role in three moments of this cycle and involved different strategies: citizen education, mobilization of social movements, and formal engagement in health councils and conferences. This brief overview of innovation cycles in the Brazilian Public Health System (SUS) and the role played by citizen participation suggests that the distributive achievements described earlier were dependent on both health system managers and social actors as well as on specific institutional arrangements that ensured regular debate between policymakers, health professionals and service user representatives. In the next section I focus on the methodology used to research the health councils which was implemented through this cycle, investigating the conditions under which they can effectively contribute to the inclusion of citizens in the policy process.



#### *4. Researching the features that contribute to deliberation and policy change*

Health councils (HCs) address core issues of priority-setting and accountability. They also approve annual plans and health budgets. If the plans and accounts are not approved, the city does not receive funding from the Health Ministry. It is important to note that although their legal powers reside mainly in the technical and administrative spheres, the councils are especially significant for their role in policy discussion (Mercadante 2000). Their substantive contribution is the expansion of public spaces with the possibility of open discussion and deliberation on health policy.

The authors who have analyzed these councils have reached ambivalent conclusions about their capacity to impact policy; while a number of cases presented relatively little achievement, there were also a number of successful cases. In these analyses, success was sometimes recognized as the capacity to include marginalized citizens, and at other times, as the ability to work as schools of citizenship or as the capacity to present innovative proposals. At still other times, success was recognized as the capacity to promote distributive gains in favor of the poor. As previously noted, these successes were interpreted as being the result of good design, or of the organization of civil society, or of the involvement by committed public managers. Nevertheless, these conclusions came through a collection of case studies, while there were not, in fact, methodological instruments to move towards a systematic comparison of these experiences. To fill this gap, we began to work on a model of analysis that would allow for evaluation and analytical integration of the drivers of change mentioned above.

The first step was to develop a model that differentiates between inclusion, connections and participation in the HCs. We also typified the debates and decisions that took place in the HCs. In doing so we worked out indicators that characterize features related to two big questions in the field: who participates and how.

Concerning inclusion, from amongst the many possible criteria, we considered as ‘more inclusive’ those indicators that reflected participants associational and political plurality, a demographic profile that mirrors that of the population, and a socio-

educational profile with significant presence of the poor and less educated. In short, we considered socio-economic, demographic, political and associative characteristics<sup>4</sup>.

Concerning connections, we assumed as ‘more connected’ those forums that presented a high level of references - in interviews with councillors and minutes of meetings - to links with the executive and legislative branches at the municipal, state, and national levels. We also refer to the connections with other participatory forums, with other institutions in the health system and with other public and private organizations.

Concerning dynamics, we looked for the features that can countervail power asymmetries between participants, and promote accountability of the participants to their constituencies, as well as the councillors’ own satisfaction with the process.

In order to investigate the impact of social mobilization on the performance of forums and on the ability to influence the policy decision making process, we selected cases (in areas with similar Human Development Indices) that had a significant history of social mobilization regarding health demands, and compared them with the results obtained for councils located in areas where there had been fewer of these mobilizations<sup>5</sup>.

Finally, we classified the debates held as: health issues, including discussions about health policies and programs and problems with service delivery; participation issues, dealing with procedures for elections and meetings; and local problems, such as water supply, infrastructure or security.

Inquiring about these features helps to describe the forums and produce data that can be used to test hypotheses related to the role of design, as well as of social and state actors in defining the performance of the forums. To understand how the decisions made by the HCs entered into the policy decision making process we interviewed public officials.

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<sup>4</sup> Tables describing these and the next variables are presented in Annex II.

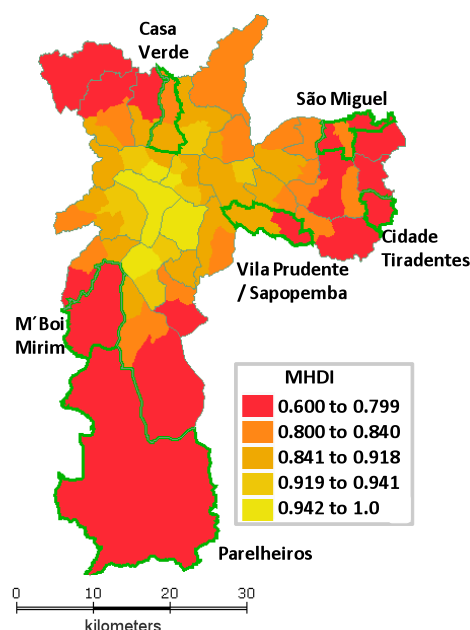
<sup>5</sup> This classification was based on secondary research and was checked in interviews with specialists on social movements in São Paulo.

In parallel with the effort to qualify citizen involvement, we monitored the distribution of public health services in order to find a plausible relationship between participation, mobilization, and distribution.

Research took place in São Paulo, which has a population of more than 11 million and which is conspicuous for its sharp social inequality and unequal access to public services. Moreover, in 2000, after the leftist Worker's Party (PT) won municipal elections, the city was divided into 31 sub-municipalities, with a Technical Health Supervisor and a Local Health Council<sup>6</sup> (CEM 2002) established in each one. It was under these conditions that we considered São Paulo to be an excellent 'laboratory' for our research.<sup>7</sup>

Map 1 presents the city with its 31 sub-municipalities and shows the Municipal Human Development Index (MHDI) figure calculated for each of them<sup>8</sup>. As shown by the data, central districts had better human development indicators. It also presents the six sub-municipalities selected for our study, which are highlighted by green boundaries.

**Map 1 – São Paulo's Sub-municipalities by Municipal Human Development Index, 2000**



Source: Atlas do Trabalho e Desenvolvimento (SMT).

Map: CEM/Cebrap

<sup>6</sup> Local Health Councils were created in a number of Brazilian metropolises to support local administration as well as Municipal Health Secretariats and councils. They have similar functions to those of the Municipal Health Council but have no veto power, since they lack a constitutional mandate.

<sup>7</sup> The study presented in this working paper builds upon previous research conducted on the creation and organization of São Paulo's thirty-one LHCs, carried out between 2001 and 2005 (Coelho, 2006), as well as on research concerning the LHC performance (Coelho, Ferraz, Fanti and Ribeiro, 2010) and the distribution of health services in the Municipality of São Paulo, carried out between 2001 and 2008 (Coelho, Dias and Fanti 2010a).

<sup>8</sup> The MHDI is constructed for each sub-municipality from the following variables: the per capita household income, the household head's average number of schooling years, the illiteracy rate of those aged 15 years and over and the population's life expectancy .

To analyze the intra-municipal distribution of health services, we ranked the city's 31 submunicipalities according to their MHDI. For each submunicipality, the percentages of SUS users were calculated<sup>9</sup> followed by the consumption rates for primary appointments and for hospital admissions in the 31 submunicipalities. We followed this distribution from 2000 to 2008. In order to facilitate description, the submunicipalities were grouped into four quartiles according to the same index (MHDI).

The 6 LHCs selected for this study are located in poor regions of the city. Three of these - São Miguel, Cidade Tiradentes, and M'Boi Mirim - had a strong history of social mobilization regarding health demands, while in the other three - Casa Verde, Vila Prudente/Sapopemba, and Parelheiros - there had been fewer of these mobilizations. To draw these distinctions we performed a review of secondary sources and reconstructed the history of mobilization in each *sub-prefeitura*. Five methods were used to describe and compare the six LHCs selected. First, we analyzed eighty-three sets of LHC minutes, covering meetings from January 2006 to August 2007<sup>10</sup>. Second, we applied a questionnaire to eighty-five councillors – a mixture of service users and health managers<sup>11</sup>; of the sixty-one who were service users, twenty-seven represented an association, while thirty-four did not. Third, we carried out participant observation of meetings. Fourth, we interviewed public officials working at the Technical Supervision. Finally, we analyzed the distribution of health services in these areas from 2001 to 2008. We expected that in areas with stronger histories of social mobilization we would find LHCs with: a) better performance (broader inclusion; broader connections; broader

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<sup>9</sup> The calculation of the SUS population is a statistical inference based on data from the National Household Sample Survey – PNAD 2003 and the 2000 Demographic Census, both from the IBGE – Brazilian Institute of Geography and Statistics. This is done by obtaining, from the PNAD, the percentage of the population that does not have health insurance (SUS users) by family income stratum in the Metropolitan Region of São Paulo; using this information, the SUS population of each sub-municipality is calculated using the product of this percentage and the distribution of family income in each of these locations according to the census.

<sup>10</sup> A standard form was created to guide the analysis and the collection of data from these minutes. To see the distribution of the minutes in the sub-districts, as well as the data gathered and used in this research, see [www.centrodametropole.org.br/v1/dados/saude/Anexos\\_Artigo\\_Saude\\_CDRCCEM.pdf](http://www.centrodametropole.org.br/v1/dados/saude/Anexos_Artigo_Saude_CDRCCEM.pdf)

<sup>11</sup> According to the Municipal Law 13 716 of 2002, regulated by Municipal Decree 44 658 of 2004, LHCs should have twenty-four effective and twenty-four substitute councillors; half should represent civil society and the other half should be split between government and service providers and health workers.

participation); b) a higher percentage of proposals aimed at addressing policy problems; and c) a higher increment in offer of services.

In the next sections I describe the research findings.

### *5. Changes in the distribution of healthcare services in São Paulo*

Analyzing available data on the supply and consumption of public healthcare services in the city of Sao Paulo for 2001, Coelho and Pedroso (2002) described a situation where despite the fact that the SUS population was concentrated in the outskirts, equipment and services were concentrated in the central and oldest areas of the city of Sao Paulo. This meant that the populations who lived in areas with better socioeconomic indicators were privileged compared to populations living in the outskirts of the city. In this sense, it is important to note that the differences in distribution measured there and in the present work are between the poor that live in different areas of the city, rather than between poor and non-poor as such.

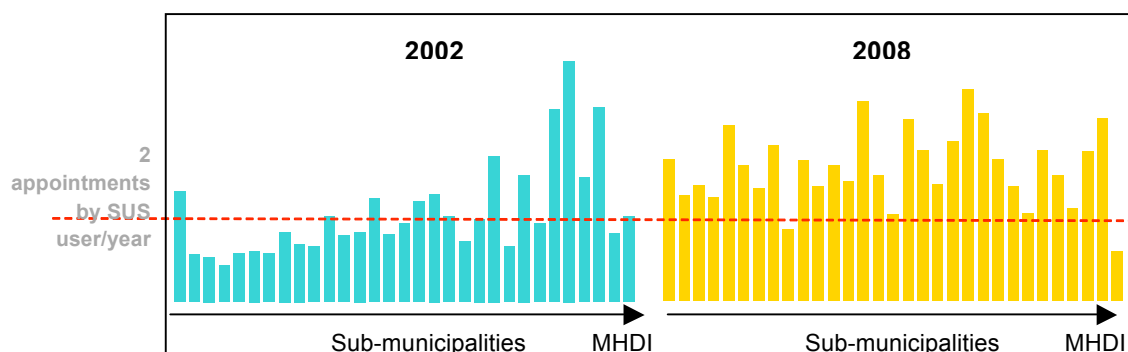
In a more recent study, Coelho, Dias and Fanti (2010) pointed out that whilst the distributive profile remained inequitable, with the highest levels of use to be found in the richest areas with the best epidemiological indicators in the municipality of São Paulo, it should be noted that there are some evidence that this pattern is changing. A higher increase in the consumption in the poorest sub-municipalities and a narrowing of the consumption gap across sub-municipalities with the highest and lowest MHDIs, can result in the reversal of the distributive trend observed<sup>12</sup>.

Chart 1 shows the distribution of basic appointments among the 31 sub-municipalities.

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<sup>12</sup> See Annex 2, Tables 1 and 2 for more details.

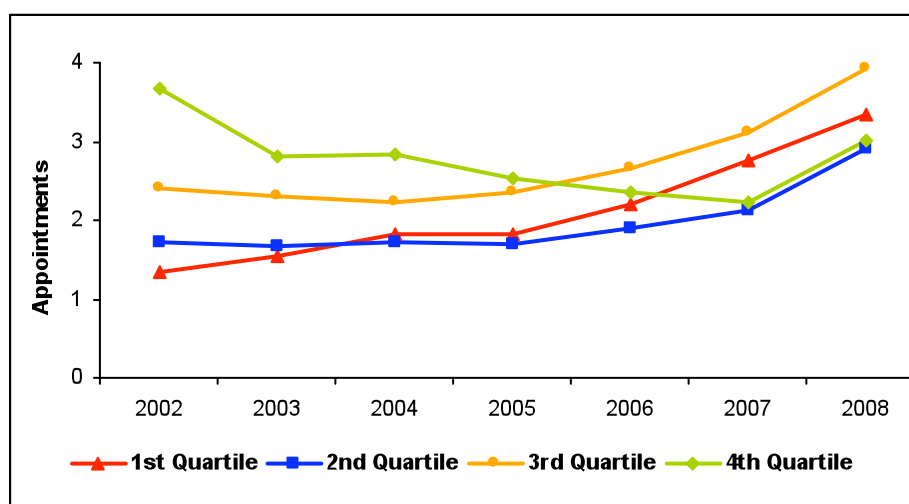
**Chart 1. Primary appointments per SUS user/year, São Paulo, 31 Sub-municipalities, 2002 and 2008**



Source: Municipal Secretariat of Health. Created by: CEM/Cebrap

The number of primary appointments increased by 68.1% between 2002 and 2008 and the average rate of basic appointments per SUS user per year went from 2.02 to 3.39. In 2002, 17 sub-municipalities (9 out of the 10 with the worst Municipal Human Development Indexes) had lower rates to that recommended by the World Health Organization (WHO), which is 2 appointments per person/year; in 2008, only 2 had inferior rates. Chart 2 shows these aggregate appointments by sub-municipality group. In this chart, the city's 31 sub-municipalities were grouped into four quartiles according to their ranking in the Municipal Human Development Index (MHDI).

**Chart 2 - Primary appointments per SUS user/year, São Paulo, Quartiles, 2002 to 2008**

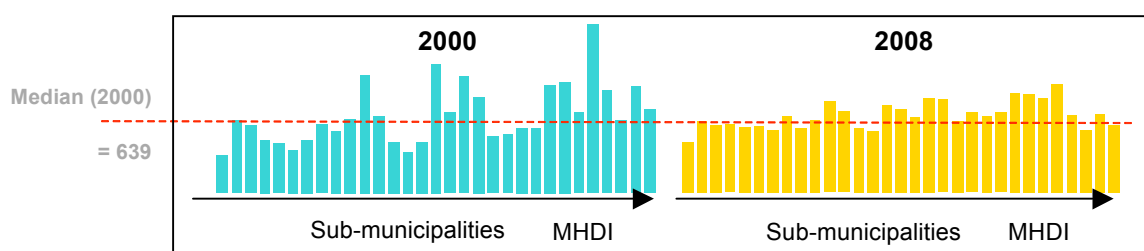


Source: Municipal Secretariat of Health. Created by: CEM/Cebrap

Charts 1 and 2 show a significant reduction in disparities in access to appointments with the standard deviation decreasing from 1.19 to 0.94. Comparing the distribution within the quartiles, the standard deviation in the fourth quartile (the wealthiest) dropped from 1.70 in 2002 to 1.14 in 2008, and within the first quartile (poorest) it increased from 0.58 to 0.64. If we divide the city into 2 groups according to their MHDI, the standard deviation in the distribution of basic appointments among the poorer sub-municipalities rose from 0.52 to 0.79 and in the richer half it dropped from 1.36 to 1.08.

Chart 3 shows the distribution of Hospital Admissions.<sup>13</sup>

**Chart 3 Hospital Admission Rate, São Paulo, 31 Sub-municipalities, 2000 and 2008**

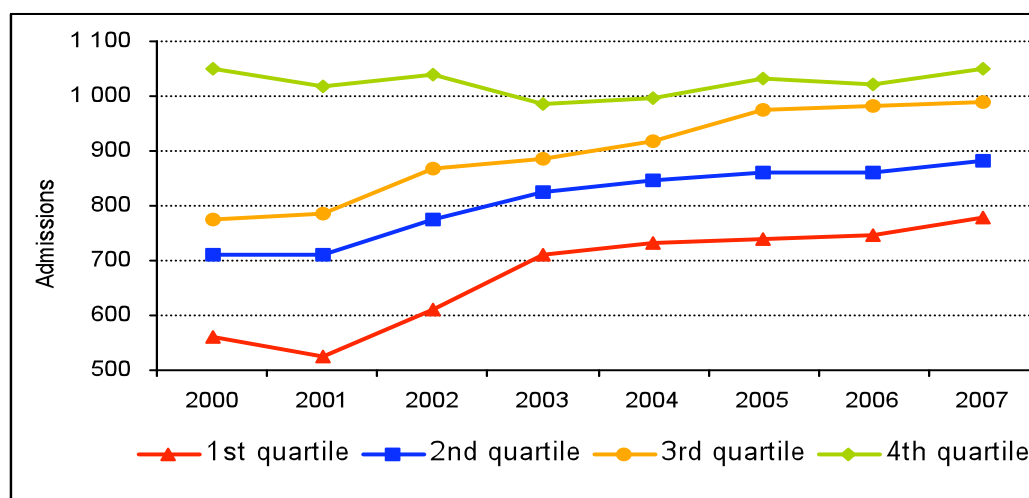


Source: Datasus – Ministry of Health. Created by: CEM/Cebrap

In 2000, 6 sub-municipalities had a rate of up to 499 hospitalizations per 10,000 users and 7 had a rate greater than 1,000. In 2008, only 1 sub-municipality had a rate of under 499 (Parelheiros) and only 1 was over 1,000 (Sé). Table 4 shows the admission rates for the municipal quartiles.

<sup>13</sup> The Authorization for Hospitalization (AIH) is the means through which healthcare service providers in Brazil are reimbursed. Each of the procedures carried out at a center are reimbursed according to a payment chart. The number of AIHs has been used to oversee the distribution of the SUS's supply of hospital beds. AIH records indicate an address for those who used the SUS service, which allows for mapping of the consumption of hospitalizations in the 31 sub-municipalities. From the absolute number, provided by the Health Secretariat, we built a rate of hospitalizations, which is the ratio between these authorizations and the population that uses the SUS (per 10,000 users).

**Chart 4 - Ratio of Consumption of Hospital Admissions per year per quartile per 10 thousand SUS users, São Paulo, 2002 to 2007**



Source: Municipal Secretariat of Health. Created by: CEM/Cebrap

Charts 3 and 4 show a significant reduction in disparities in hospital admissions. The standard deviation in the distribution of Hospital Admissions dropped from 297 to 131. In a comparison of the distribution among the quartiles, the standard deviation in the first quartile (poorest) went from 120 in 2000 to 73 in 2008, and within the 4th quartile (wealthiest) it fell from 309 to 163. If we divide the city into 2 groups according to MHDI, the standard deviation in the distribution of Authorizations for Hospitalization among the poorest sub-municipalities decreased from 270 to 103 and in the richer half it went from 281 to 128.

*In short*, the data collected here clearly shows that the distribution of public healthcare services in Sao Paulo became more equitable. There was significant expansion in the supply as well in the consumption of services in the regions that present the worst socio-economic and health indicators. The analysis of the distribution of these resources showed that we now have a more equitable distribution pattern of public health services between locations with a reduction in the geographic inequalities hindering access to the public health system. What is not in line with this scenario are the increased differences (reflected in the rise in standard deviation) in the rates of basic



appointments recorded in the sub-municipalities that have the worst socio-economic and health indicators.

Looking specifically at the areas under study and exploring the possible distributive impacts of participatory dynamics that are taking place in the sub-municipalities, we found that of the eight sub-municipalities on the city's outskirts that presented low MDHIs, only two have municipal hospitals that were built in the period, namely Cidade Tiradentes and M'Boi Mirim, which have active councils. When we compared the number of Outpatient Health Units (AMAs) operating in these sub-municipalities, we found that there were 16 units in the three sub-municipalities that have the most active councils vis-à-vis 10 in the areas where the councils are less active. In this case, the second group should have had 15 units if distribution had merely followed population distribution criteria.

#### *6. Comparing citizen involvement*

The local health council (LHC) consists of 24 effective and 24 substitute councilors. In the LHCs studied, the councilors that represent civil society self-identified themselves as representatives of: popular health movements; health units; religious associations; neighborhood associations; Unions; civil rights groups; participatory forums; homelessness movements; landless peasants movements; community or philanthropic groups; disabled persons associations; or as non-affiliated representatives (Coelho, 2006).

The tables and graphs presenting the indicators calculated for the three dimensions under study – inclusion, connections and dynamics – as well as the analysis of the debates held are presented in Annex II. The presence of a background of social mobilization proved itself to be an important factor in promoting more vibrant LHCs as well as in increasing the participation of the most vulnerable as shown by the greater inclusion of councillors with less education and women and non-whites on the councils located in the *sub-prefeituras* which had stronger backgrounds of mobilization. Also, the way debates are carried out is very different in areas with a greater or lesser history of mobilization. The results pointed out that in the sub-municipalities with a stronger history of mobilization, the LHC discussions were marked by more conflict and

confrontation, but had better outcomes in the variables related to monitoring healthcare services and innovative proposals. As an example, in regards to the reduction of absenteeism, one suggestion made by the LHC that was implemented was to contact patients advising them of the date of the appointment. Also, monitoring of the construction of the two municipal hospitals built in the period helped in speeding the process. The organizations and the councils for these areas also present a greater number of connections with socio-political and institutional actors and have links to segments of bureaucracy, service providers, politicians and the civil society (Coelho, Ferraz, Fanti and Ribeiro 2010).

We also noted that in more mobilized areas this dynamic has contributed to promoting greater integration between the councils and their respective Technical Health Supervision Units (Coelho, Dias and Fanti 2010). In a situation of heated disputes over resources between sub-municipalities, this integration with councils has been welcomed by supervisors of the Technical Units. After all, those with the support and endorsement of civil society will be in a better position to negotiate their demands with the Municipal Secretariat of Health. The gains from this strategy are reflected in the increased ability to raise funds as shown by the three sub-municipalities which have more active councils. For example, as noted previously, the only two municipal hospitals opened in the period were built in Cidade Tiradentes and M'Boi Mirim. Another example is given by the greater number of recently inaugurated Outpatient Health Units in these sub-municipalities. These results help to explain a distributive tendency reported earlier: a reduction in inequalities in the supply of services among areas that have the best and the worst socio-economic and health indicators, as well as a slight increase in inequalities in distribution of basic services within areas with the worst indicators (Coelho, Dias and Fanti 2010).

The results also have shown that in both areas, with greater and lesser mobilization, 'vivid' participation is limited, inasmuch as few councillors raised issues and sustained discussions about them. In this sense, the creation of these LHCs, which are testaments to an impressive institutional process of building participatory forums, was not accompanied by innovation in the day-to-day operation of these spaces. In many cases they contributed, in the more mobilized areas, to simply reproducing the positions of health movements. Curiously enough, in the group with weaker

backgrounds of mobilization, aspects associated with procedures - design and election themes - appeared more frequently, suggesting that these LHCs are looking for changes in their dynamics.

These results are summarized in Table 1

**Table 1 - Differences between Local Health Councils in areas with weaker and stronger mobilization**

LHC in areas of Weak Mobilization	LHC in areas of Strong Mobilization
↓ Socio demographic inclusion	↑ Socio demographic inclusion
↑ Political and associational inclusion	↓ Political and associational inclusion
↓ Connections	↑ Connections
↑ Procedural innovations	↓ Procedural innovations
↓ Deliberation	↓ Deliberation
↓ Monitoring innovation	↑ Monitoring innovation
0 Municipal Hospitals	2 Municipal Hospitals
10 outpatients units	16 outpatients units

Source: Health policy and public involvement in the city of São Paulo Project, 2009 – CDRC/CEM/NCD

Despite the small number of cases analyzed, they suggest interesting relations between mobilization, LHCs and distributive impacts, drawing attention to the non-linearity of the gains described. The dimensions - inclusion, participation, and connections - and the indicators that we have chosen to represent them run in different directions, highlighting the complexities of citizen involvement in the policy process. In

the councils located in the sub-municipalities with a stronger history of mobilization, we found greater socio-economic inclusion, but less political and associative plurality. Also, the discussions were less deliberative, marked by more conflict and confrontation and more resistance was offered to change in the procedures used to select representatives and organize the meetings. Yet, at the same time, better outcomes were presented in monitoring healthcare services and raising funds. On the other hand, the LHCs located in areas with less history of mobilization are the ones that worked out propositions to change procedures, which may favor new and more deliberative dynamics. They are searching for new ways to select the councillors and run meetings (Coelho et al. 2010).

On a final note, it is worth mentioning that in the last fifteen years growing resources have been expended in public health. However, the probability of continuing expansion is slight<sup>14</sup>. At the same time, other issues related to service quality, rising costs and an aging population are coming to the fore. In this scenario, it remains to be seen if the mechanism described that links mobilization, participation and distribution will endure or if new mechanisms, including more effective deliberation, will have to be considered. We turn to this discussion in the next section.

##### *5. Reimagining citizen involvement in the SUS*

In this paper I have departed from the literature calling attention to the potential of mobilization, participation and deliberation in contributing to the democratization of the decision making process and its increased accountability to citizens. I have also reviewed a number of studies that researched empirical experiments concerning citizens' involvement in the policy process. While the empirical findings confirm the relevance of the theoretical approaches to explain successful cases, they call attention to the fact that in most cases these perspectives have been studied separately. They also point out to the fact that there are several case studies while there are few systematic comparative studies in these fields.

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<sup>14</sup> In 1995, public expenditures reached US\$17 billion, going to US\$28 billion in 2006 (figures restated to reflect the worth of a dollar in 2000). In 2006, total expenditures were equal to 7.5% of the GDP (US\$ 58.5 billion), of which 48% were public expenditures and 51% were private expenditures.

In order to approximate these debates and allow for more systematic analyses, I have presented an innovative comparative research framework designed to make inquiries into the relations between forum features, social mobilization, the capacity of these forums to influence policy, and to promote distributive impacts. Research has been focused on health councils that are part of a national framework for citizen involvement in health policy implemented during the mandate of political parties that supported the cause of greater citizen involvement. These councils were conceived as public spaces that could promote deliberation between civil society, public managers and service providers on health policy.

This research framework was tested with a small selection of cases. Despite the number of cases analyzed, the results suggest that in a context of growing public health expenditures, federal inducement of health programs and governments that are supportive of the cause of participation, a positive association did occur between, on the one hand, mobilized social actors, their participation in health forums and the building of alliances with health managers, and on the other hand, a growing offer of health services to poor areas. This mechanism is probably similar to those that linked the health movement, health councils and health authorities throughout Brazil over the last twenty years and helped to promote greater equality in inter and intra regional distribution of public health services. However, the results also call attention to a negative association between both mobilization and deliberation, as well as to a slight increase in inequality in the distribution of basic services within the poorest areas of the Municipality of São Paulo.

These results should not be read as an indication of the need to insulate the councils from more politicized actors. To the contrary, mobilization brought dynamism to the forums and proved important in guaranteeing the inclusion of women, non-whites and non-educated people in the health councils, as well as in promoting the councils' connection with state, social and market actors, which helped to disseminate the debates and struggles. The result was an increased ability to negotiate and bring health services to poor areas, contributing to diminish inequalities. Nevertheless, the results also suggest that deliberative dialogue is very much needed as it can help to tackle the risk of exacerbated horizontal inequalities between mobilized and non-mobilized poor communities. Deliberation may also amplify the capacity of these forums to deal with

‘second order’ themes such as, for example, issues of quality, of priority setting in a context of less elastic resources, and of more controversial ethical problems related to life and death.

The remaining question is how a more positive relationship between mobilization, deliberation and distribution can be established. The question is not an easy one since a number of studies have already noted that in practice, rather than being spaces for the convergence of different interests, forums designed for citizen involvement in the policy making process are themselves an expression of specific coalitions (Coelho and Favareto 2008). In this scenario I would suggest that the answer cannot be sought exclusively in the daily routine of the political arena. An important part of the work will have to be done in another arena: the early education of public officials and politicians in deliberative techniques. Once they learn more about the rationale and procedures associated with deliberation, they may work towards the inclusion of a broader spectrum of actors in participatory arenas debates, as well as towards reducing the asymmetries between them, contributing to fostering genuine deliberative dialogues between experienced political actors and the less politicized.

In addition, the training of public officials and politicians can bring a decisive contribution to the development of more systematic connections between the councils and government bodies. These connections can be facilitated, for example, by the ways by which the debates and recommendations made by the councils are synthesized and presented (for example, format and scope). In the councils under discussion, for instance, there is still very little work that has been done to bring together the myriad of suggestions and criticisms worked out by the councilors. More investment in this area would go some distance in helping to rescue the richness of involving citizens, managers, researchers and service providers in policy debates as well as in preparing these materials to be used more effectively during other stages of the policy process. Also core to strengthening the capacity of those forums to attract a broader spectrum of actors is the political decision of making the connection clearer between participation and the capacity to influence the channeling of resources in order to deliver public tangible benefits.

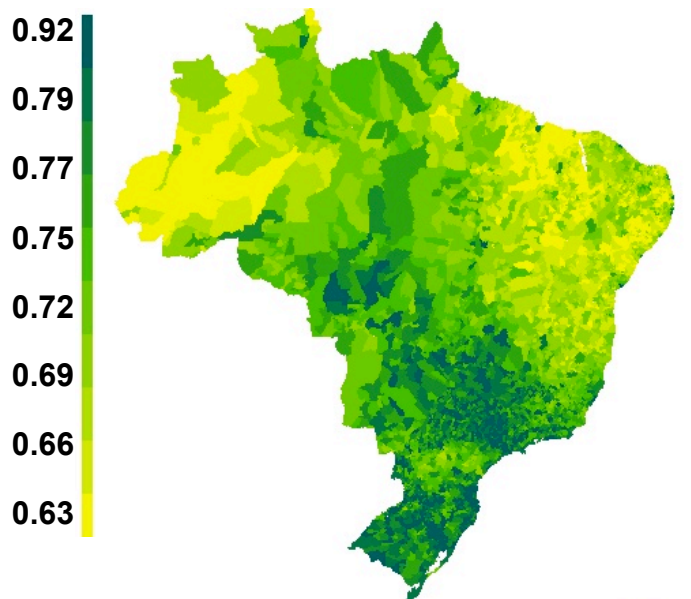
Another arena that deserves attention is the early education of citizens concerning their right to participate. Over the last twenty years, Brazil has built an incredible participatory governance structure, but citizens still know very little about its existence. One possible way to fill this gap is to include information on educational curricula, from primary education to higher learning, concerning the variety of accessible channels provided to citizens so that they may participate in the process of discussing, drafting, and monitoring a wide range of public policies.

In short, the Brazilian experience with health councils offers important lessons concerning the possibilities of building a national network for citizen involvement in health policy as well as the distributive effectiveness of mechanisms that link social mobilization, participation and public officials. This experience suggests that insofar as the political parties and system managers acknowledge social actors as partners they gained an important ally in their struggle to overcome a biased and inequitable distributive profile. This disposition to acknowledge social actors as partners is not a trivial one; also, the very existence of organized social actors interested and capable of acting as partners cannot always be relied upon. Nevertheless, the case also calls attention to the risks of these mechanisms in reinforcing the exclusion of the less mobilized while promoting greater horizontal inequalities. As a practical suggestion, in order to maintain gains and avoid risks, I would recommend that more attention should be given to the early education of citizens on their right to participate and to training public officials and politicians in deliberative techniques, since this may help in fostering the features of participatory governance related to inclusion of ordinary citizens, along with their values, positions and preferences, in the political process.

## Annex

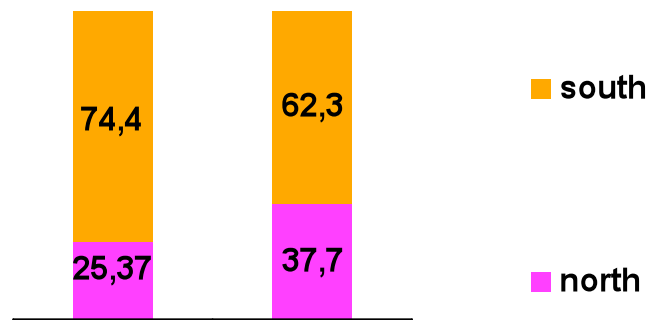
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**Municipal HDI - 2000**



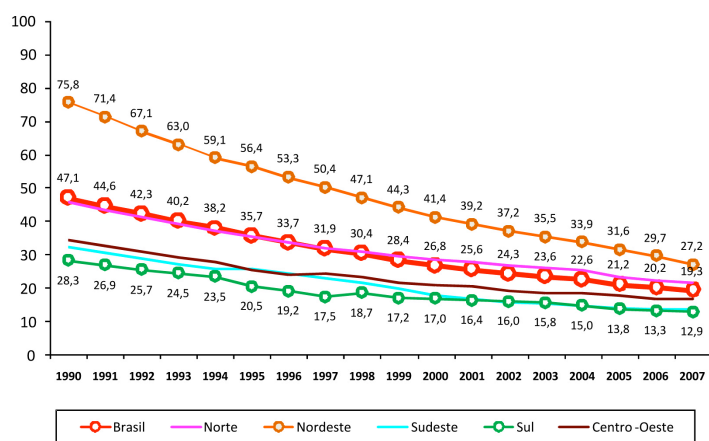
Source:  
Inea

**Regional Distribution of resources for health assistance, 1986-2006**



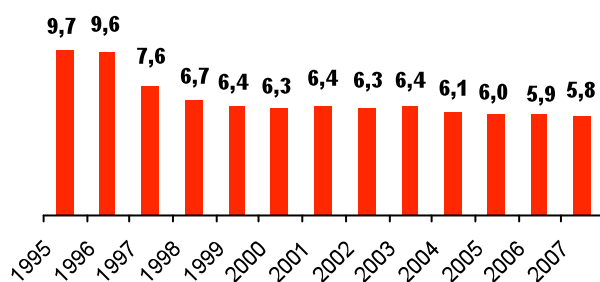
Source: SAS/MS (1986); Siops (2006)

**BRAZIL - Infant Mortality Rate (per 1000 live births)**



Source: MS  
2010

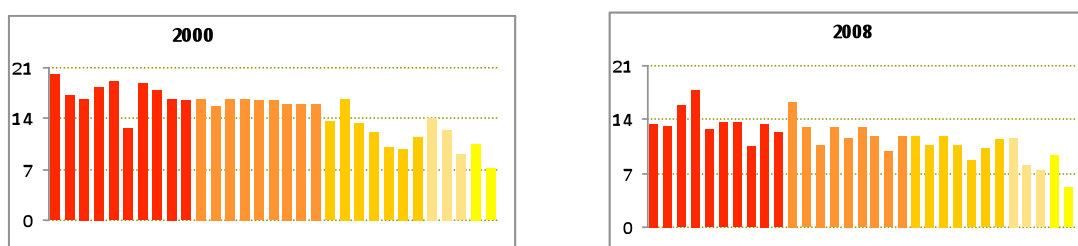
**Aids Mortality Rate (Death per 100.000 habitants)**



Source: Monitoraids,  
2008



## Infant Mortality Rate, São Paulo, Sub-Municipalities, 2000 and 2008



**São Paulo's sub-municipalities, ordered by crescent HDI**

Source: Municipal Health Secretary. Chart: CEM/Cebrap

## Annex

**Table 1. Primary appointments per SUS user/year, São Paulo, Quartiles, 2002 and 2008**

		Number of Appointments		Number of Appointments		Relative Increase
		2002		2008		2002-2008
Quartiles	MHDI	Total	Per SUS user	Total	Per SUS user	%
1st quartile	0.77	1,880,929	1.33	5,148,808	3.35	173.7
2nd quartile	0.81	3,160,668	1.73	5,648,032	2.91	78.7
3rd quartile	0.85	3,122,877	2.41	5,126,034	3.94	64.1
4th quartile	0.93	2,487,788	3.68	1,982,058	3.02	-20.3
<b>São Paulo</b>	<b>0.84</b>	<b>10,652,262</b>	<b>2.00</b>	<b>17,904,922</b>	<b>3.20</b>	<b>68.1</b>

Source: Datasus – Ministry of Health. Created by: CEM/Cebrap

**Table 2. Hospital Admission Rate, São Paulo, Quartiles, 2000 and 2008**

		Admissions		Admissions		Relative Increase
		2000		2008		2002-2008
Quartiles	MHDI	Total	Per 10,000 SUS users	Total	Per 10,000 SUS users	%
1st quartile	0.77	76,752	561	106,565	642	14.4
2nd quartile	0.81	126,613	710	153,373	731	3.0
3rd quartile	0.85	100,064	774	115,507	802	3.6
4th quartile	0.93	71,941	1,052	62,375	851	-19.1
<b>São Paulo</b>	<b>0.84</b>	<b>375,370</b>	<b>745</b>	<b>437,820</b>	<b>744<sup>i</sup></b>	<b>0.1</b>

Source: Datasus – Ministry of Health. Created by: CEM/Cebrap

**Tab. 3 – Types of inclusion in six CLSs located in areas with different histories of**

Indicator	Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parel-heiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Gender	similarity to distribution in the population.	1	0	0	0	1	1
Skin colour	similarity to distribution of whites and non-whites in the population.	0	0	0	1	0	1
Education	representation of councillors with low level of education.	0	0	0	1	0	1
Income	representation of councillors with low income.	0	1	0	1	0	1
Party plurality	presence of representatives across the political spectrum.	1	1	1	0	0	0
Associations	number of types of association represented.	1	0	1	0	1	0

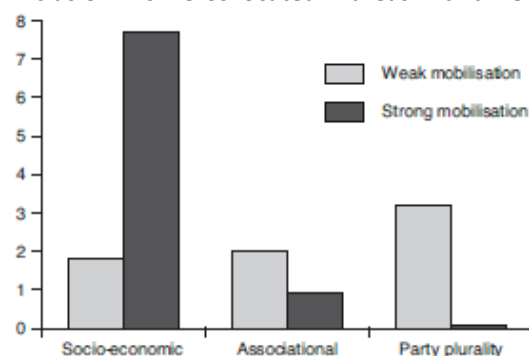
Lighter grey: sub-prefeituras with a weaker history of mobilization.

Darker grey: sub-prefeituras with a stronger history of mobilization.

Note: 1. Councillors reported themselves as representatives of popular health movements, health units, religious associations, neighbourhood associations, unions, civil rights groups, participatory fora, homelessness movements, the landless peasants movement, community or philanthropic groups, disabled persons associations, or as non-affiliated representatives.

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Graf. 1 - Types of inclusion in six CLSs located in areas with different histories of mobilization**



Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Tab. 4 Connections by six CLSs located in areas with different histories of mobilization**

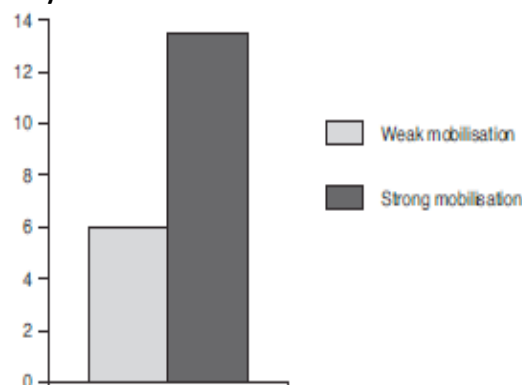
Indicator	Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parel-heiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Manager	mentioned by councillors in questionnaire.	0	0	1	0	1	0
Politician	mentioned by councillors in questionnaire.	0	0	0	0	1	1
State body	cited in council minutes.	0	1	0	1	0	0
Executive and Legislature	identified by councillors as having a relationship with the organizations they represent	1	0	0	0	1	1
Health Unit	cited in council minutes.	0	1	0	1	1	0
Organization	cited in council minutes.	0	0	1	0	1	1
Association	councillors representing an association.	0	0	1	0	1	1
Participatory Forum	cited in council minutes	0	0	0	1	1	0

Lighter grey: sub-prefeituras with a weaker history of mobilization.

Darker grey: sub-prefeituras with a stronger history of mobilization.

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Graf. 2 - Connections by six CLSs located in areas with different histories of mobilization**



Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Tab. 5 - Features of Participation in six CLS located in**

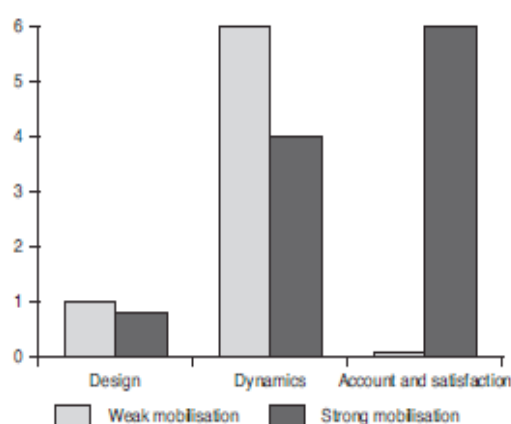
Indicator	Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parelheiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Selection procedure	transparency in selection of councillors.	0	0	0	0	0	0
Facilitation	Presence of facilitator.	0	0	0	0	0	0
Agenda	% of meetings coordinated by non-manager councillors.	0	1	0	0	1	0
Themes	balance of themes on council agenda.	0	0	1	1	0	0
Right to speak	participation of non-manager councillors.	0	1	1	0	0	1
Right to speak	participation of non-councillors.	0	1	0	0	0	1
Environment	number of councillors contributing in council meeting.	0	1	0	0	1	0
Environment	number of times a single councillor contributed in a council meeting.	0	1	1	1	0	0
Accountability	number of media used by councillors to keep constituencies informed.	0	0	0	1	1	1
Satisfaction	councillor satisfaction about running of council	0	0	0	1	1	1

Lighter grey: sub-prefeituras with a weaker history of mobilization.

Darker grey: sub-prefeituras with a stronger history of mobilization.

Note: 1. The value 1 was attributed to the councils where the agenda presents an equilibrium between issues concerning health policies; specific problems in the local health units; regional problems and procedures connected to the functioning of the forums.

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Graf. 3 - Features of Participation in six CLS located in areas with different histories of mobilization**

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

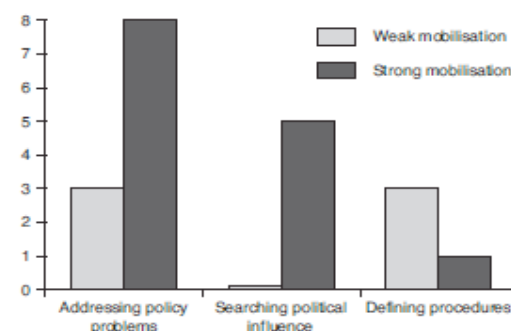
**Tab. 6 - Type of theme debated in six CLSs in areas with different histories of**

Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parelheiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Positioning about policy issues or making demands.	0	0	1	1	1	1
Planning, partnership or innovation.	0	0	1	1	1	1
Monitoring.	0	0	1	1	1	0
Recognizing cultural and ethnic diversity.	0	0	0	1	1	1
Expanding political influence.	0	0	0	1	1	0
Defining procedures for participation and electoral processes.	1	1	1	1	0	0

Lighter grey: sub-prefeituras with a weaker history of mobilization.

Darker grey: sub-prefeituras with a stronger history of mobilization.

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Graf. 4 - Type of theme debated in six CLSs in areas with different histories of mobilization**

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

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